



Journal of Nursing

Revista de Enfermagem

UFPE On Line

ISSN: 1981-8963

REFLECTIVE ANALYSIS ARTICLE

CHALLENGES FOR FAMILY CAREGIVERS OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS: CONTRIBUTIONS OF NURSING

DESAFIOS PARA OS CUIDADORES FAMILIARES DE CRIANÇAS COM NECESSIDADES ESPECIAIS DE SAÚDE: CONTRIBUIÇÕES DA ENFERMAGEM

DESAFÍOS PARA CUIDADORES FAMILIARES DE NIÑOS CON NECESIDADES MÉDICAS ESPECIALES: CONTRIBUCIONES DE ENFERMERÍA

Eliane Tatsch Neves¹, Andressa da Silveira²

ABSTRACT

Objective: to reflect on the challenges faced by family carers of children with special health care needs (CRIANES) for the care of those at home. **Method:** a descriptive study, reflection type, which presents the contribution of technological progress and its impact on child health, which is reflected in the reduction of child mortality in contrast to the increasing number of children with chronic conditions and who require health services beyond that required by other children, CRIANES. **Results:** among the many challenges in the daily care of CRIANES highlight the need for home care and the difficulty of access to services for the monitoring of these children in the context of community. **Conclusion:** there is a need to promote the empowerment of the family caregiver for this child care practice, enabling that group to access health services in the community. **Descriptors:** Nursing; Child Health; Chronic Disease; Pediatric Nursing.

RESUMO

Objetivo: refletir sobre os desafios enfrentados pelos familiares cuidadores de crianças com necessidades especiais de saúde (CRIANES), para o cuidado destas no domicílio. **Método:** estudo descritivo, tipo reflexão, que apresenta a contribuição do progresso tecnológico e suas repercussões na saúde da criança, as quais se refletem na redução da mortalidade infantil em contraponto ao aumento do número de crianças com afecções crônicas e que necessitam dos serviços de saúde para além do exigido por outras crianças, as CRIANES. **Resultados:** dentre os diversos desafios no cotidiano de cuidar de CRIANES destacam-se a necessidade do cuidado domiciliar e a dificuldade de acesso aos serviços para o acompanhamento dessas crianças no contexto da comunidade. **Conclusão:** há a necessidade de promover o empoderamento do familiar cuidador, para a prática de cuidado dessa criança, possibilitando o acesso desse grupo aos serviços de saúde na comunidade. **Descritores:** Enfermagem; Saúde da Criança; Doença Crônica; Enfermagem Pediátrica.

RESUMEN

Objetivo: reflexionar sobre los desafíos enfrentados por los familiares cuidadores de niños con necesidades especiales de salud (CRIANES) para el cuidado de estos niños a domicilio. **Método:** estudio descriptivo, tipo reflexión, que presenta la contribución del progreso tecnológico y sus repercusiones en la salud del niño, las cuales se reflejan en la reducción de la mortalidad infantil en contraste al aumento del número de niños con afecciones crónicas y que necesitan servicios de sanidad más allá de lo exigido por otros niños, la CRIANES. **Resultados:** de entre los diversos desafíos en lo cotidiano de cuidar de CRIANES se destacan las necesidades de cuidado a domicilio y la dificultad de acceso a los servicios para el acompañamiento de estos niños en el contexto de la comunidad. **Conclusión:** existe la necesidad de fomentar los poderes del familiar cuidador para la práctica del cuidado del niño, permitiendo el acceso de este grupo a los servicios de sanidad en la comunidad. **Descriptores:** Enfermería; Salud del Niño; Enfermedad Crónica; Enfermedad Pediátrica.

¹Nurse Pediatrician Professor PhD, Department of Nursing / Graduate Program in Nursing, Federal University of Santa Maria / UFSM. Santa Maria (RS), Brazil. E-mail: elianeves03@gmail.com; ²Nurse, Professor Master in Nursing, School of Nursing, Federal University of Pampa / UNIPAMPA. Santa Maria (RS), Brazil. E-mail: andressadasilveira@gmail.com

INTRODUCTION

The neonatal care has advanced greatly in recent decades with the introduction of therapeutic and technological resources more effective and specialized human resources. The care in this area underwent changes over time, under the influence political, economic, cultural and social, reflected in Brazil, mainly with the importation of respirators and incubators in the 1960s.¹ This importation has intensified in the 50's, was broadcast by hospitals in the 60's and had its prominence in child care in the 70's.

With these technological advances introduced in the health care of the child obtained the reduction of child mortality and increased survival of medically fragile children. It is understood, therefore, that this technological progress contributed to rising rates of children with chronic / disabling, among which many need some kind of technology to maintain their survival.²

Technological development has helped to prevent the death of children with chronic / disabling because without these features, they do not maintain alive.¹ This led to the emergence of a group of technology-dependent children and / or health care, called, from 1995 in the international literature, the Maternal and Children Health Bureau, as Children with Special Health Care Needs (CSHCN), and in Brazil, from 1999 to crianças com necessidades especiais de saúde (CRIANES).³⁻⁴

Regardless of the care demands presented by CSHCN it is necessary to consider them as a clientele emerging in pediatric nursing because of the diversity of care required by them. Stands out as characteristic of this group of children the uniqueness of care being considered supernatural by its complex nature and the clinical fragility of these children.⁵⁻⁶ They have also vulnerabilities social, programmatic and individual. All these aspects pose challenges not only for the health care team, but also for the family caregiver who keeps CSHCN care at home.⁷

The CSHCN pose challenges for health professionals, especially for nursing professionals who face admissions and readmissions to emphasize the complexity of the child's diagnosis and medication. For family caregivers challenges are magnified, since they have the challenge of caring for a child at home with modified usual care, which makes continuous medication with technologies deployed in your body, requiring

constant vigilance and dedication sole caregiver family.⁸

In Brazil, there are no official estimates on the number of CSHCN among the general population. However, one can identify the growth of this group in epidemiological rates inversely proportional to the reduction of infant mortality, a result of increased survival, as studies have pointed out the reality of other countries and Brazil.⁹⁻¹⁰ In this country, the increase in this group relates to three factors: children with preventable diseases that have their health chronified due to hospitalizations and readmissions, children with perinatal that due to a long period of intensive treatment, develop complex diseases, and children with congenital malformations that result in the need for a periodic health monitoring for an indefinite period.

Despite official rates suggest a decrease in mortality due to perinatal conditions in Brazil, in the period between 2000 and 2008 was 14.7 to 10.3 per 1000 live births and Rio Grande do Sul (southern Brazil) was 7.9 to 7.511 because this implies a significant number of children who survive presented demands special health care needs. In this sense, the respiratory diseases is the mainly complication presented by CSHCN and they represented 40.3% of the causes of hospitalizations (in the public health services) among children under four years between 1998 and 2007.¹²

The invisibility in official rates implies programmatic vulnerability of these clients, since there are no specific policies for them, and often they needs resort to judicial decisions for the CSHCN can have access to services and facilities essential to their treatment / monitoring health.

The clinical fragility of CSHCN involves exposure to sickness and risk of death due to discontinuation of medications for their survival, the inadequacy in handling bodily technologies or equipment required for the administration of medications.⁵ This fragility denotes the individual vulnerability of these children who need a caregiver. Already the social vulnerability of CSHCN is linked to low income families often insufficient to meet the minimum demands of these children, and the lack of knowledge of family / caregivers about the special healthcare needs children's rights to social programs.⁵

This article reflects on the challenges for to take care of the children with special healthcare needs at home faced by their family caregivers.

Among the many challenges faced in the daily care of CSHCN by both family caregivers as health professionals, this article highlighted the need for homecare of CSHCN - familial care and difficulty of access and monitoring of health status of these children in the context of community .

• **The need of homecare to CSHCN - familial care**

After discharge from CSHCN, family members face the reality of caring for a special child who needs some kind of device on your body or drugs to survive. These children standards require complex care, so care provided to them by professionals and family care differs grasped by common sense. This care needs to be developed in the home, although in this environment does not exist the same technologies available in the hospital.⁴

At the time of hospital discharge, the family of CSHCN became the main caregivers of these children, requiring often abnegation of social life to devote himself to the specific care that the child needs. Caring for a child with technological dependence in the household leads to disorganization of the family in various dimensions of life, as well as routine activities.¹³ Children with special health care needs, when at home, require continuous care of a complex nature, care techniques routinely performed in hospital (probing, vacuum, bed bath, care drains, dressings, among other procedures), which now procedures be performed at home by family caregivers, requiring dexterity, management and adaptation of the home environment for care. In this context, the need to mediate care practices with these families is based on the fundamental knowledge of nursing.¹⁴

Thus, the nursing staff needs to negotiate the knowledge and practices which are necessary to address the multiple care demands of these children at home. And thus, mediate knowledge needed to develop the CSHCN care, considering it is a complex for nursing, which is faced with this clientele invisibility in official rates and public policy. Show up as problems in practice, the distance of these families the care planning of health professionals, including nurse practitioners, as well as the lack of social network that could support them in health care and quality of life of CSHCN within the home.

Family caregivers of CSHCN, in general, are women living in a situation of oppression that causes suffering and stress, compromising their well-being. To be a good mother, given

the legacy of moral obligation, the women caregivers should be thoughtful, dedicated, zealous and self-sacrificing his social life.¹⁵ This leads them to social isolation, suffering and stress, negatively affecting their health status.

• **The difficulty to access the services and monitoring the health status of CSHCN in the context of community**

Although the Brazilian law of the public health system (Sistema único de Saúde - SUS) guarantees the right to health and access to all, equally, the relatives of CSHCN often faced with the difficulty of access to health services, and system failures reference and counter. Social support is fragile, being reduced to the family network and the nearest hospital. In many cases, the CSHCN only have access to health services when the family is empowered and tries to get the child's treatment; they weave a network of support grounded in favors from friends who work in this health services.^{7,16-17} This violates the principles of comprehensiveness and universality of access advocates by Brazilian public health system (SUS)¹⁸.

The CSHCN require a set of services that work towards the rehabilitation, accordingly, need a social support network that provides support to family caregivers. This network of support should go beyond medical and nursing care, including the needs of children and the family caregiver in their daily lives.⁷

In relation to the political and social landscape, the current legislation does not provide specific policies for these clients, who hinders the access and support through social networks to caregivers CSHCN. It is, therefore, a recurrent problem, reported by these authors, who develop studies aimed both at children with chronic diseases, as those with special healthcare needs. It is noted also that the legal support and policy is critical to support family caregivers of these children, as the demand for care provided by them in everyday life is already quite complex.

However, not just the right to be guaranteed in legislation and public policies in force so that it is actually implemented. Research conducted with CSHCN in recent years have revealed that there is a long way that still separates these children's rights guaranteed by the law and the enforcement of rights in practice.¹⁹

CONCLUSION

The challenges of caring for a home in CSHCN underlie the need to grasp knowledge and practices that are not part of the daily life of family caregivers and the difficulty of access to health services for continuing care of those children.

In this context, family caregivers need to weave their own support networks, based on the daily struggle that includes pilgrimage to various services, judicial and use of privileged contacts, injuring principles of the public health system.

It is necessary to give visibility to this group child glimpsing nursing care that addresses the uniqueness of the child and his family, in view of the epidemiological and political dimension of care. With the unveiling of visibility, it is thought the effective inclusion of the issue of CSHCN in discussions of public policy in Brazil, in the academic space, as has occurred in other countries of North America.

Health professionals, including nursing staff, need to pay attention to these clients, assisting families who suddenly find themselves in the role of taking care of a technology-dependent child in the household. Accordingly, we recommend the development of a family-centered care, and health education as a strategy of empowerment of family caregivers of CSHCN.

We conclude that there is a long way to go to achieve the recognition of the existence of this group, in Brazil,, the need to promote the empowerment of the family caregiver for this child care practice, enabling that group to access health services in the community.

REFERENCES

- Oliveira ICS. A história da tecnologia e suas repercussões no cuidar em saúde da criança. Esc Anna Nery Rev Enferm [Internet]. 2002 Dec [cited 2013 Jan 17]; 6(1): 101-6. Available from: <http://bases.bireme.br/cgi-bin/wxislind.exe/iah/online/?IscScript=iah/iah.xis&src=google&base=LILACS&lang=p&nextAction=lnk&exprSearch=446843&indexSearch=ID>
- Wong D. Enfermagem Pediátrica: elementos essenciais à intervenção efetiva. 5. ed. Rio de Janeiro: Guanabara Koogan; 1999.
- McPherson MG, Arango P, Fox H, Lauver C, McManus M, Newachek PW, et al. A new definition of children with special health care needs. Pediatrics [Internet]. 1998 July [cited 2013 Jan 17];102(1):137-41. Available from: <http://pediatrics.aappublications.org/content/102/1/137.full.pdf+html>
- Cabral IE. Aliança de saberes no cuidado e estimulação da criança-bebê: concepções de estudantes e mães no espaço acadêmico de enfermagem. Rio de Janeiro: Anna Nery; 1999.
- Neves ET, Cabral IE. A fragilidade clínica e a vulnerabilidade social das crianças com necessidades especiais de saúde. Rev gaúch enferm [Internet]. 2008 June [cited 2012 Jan 10];29(2):182-90. Available from: <http://seer.ufrgs.br/RevistaGauchadeEnfermagem/article/view/5533/3150>
- Neves ET, Cabral IE. Cuidar de crianças com necessidades especiais de saúde: desafios para as famílias e enfermagem pediátrica. Rev eletrônica enferm [Internet]. 2009 Sept [cited 2011 Oct 15];11(3): 527-38. Available from: <http://www.fen.ufg.br/revista/v11/n3/v11n3a09.htm>
- Silveira A, Neves ET. Crianças com necessidades especiais de saúde: tendências das pesquisas em enfermagem. R enferm UFSM [Internet]. 2011 May-Aug [cited 2012 Jan 13];1(2):254-60. Available from: <http://cascavel.ufsm.br/revistas/ojs-2.2.2/index.php/reufsm/article/view/2526/1640>
- Beuter M, Rossi JR, Neves ET, Brondani CM. Caregiver burden in the homecare. Rev enferm UFPE on line [Internet]. 2009 July-Sept [cited 2011 Dec 10];3(3):256-62. Available from: <http://www.ufpe.br/revistaenfermagem/index.php/revista/article/view/181/181>
- Newachek PW, Bonnie Strickland B, Shonkoff JP, Perrin JM, McPherson MG, McManus M et al. An epidemiologic profile of children with special health care needs. Pediatrics [Internet]. 1998 July [cited 2012 June 11];102(1):117-23. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/9651423>
- Van Dyck PC, Kogan MD, McPherson MG, Weissman GR, Newachek PW. Prevalence and characteristics of children with special health care needs. Arch Pediatr Adolesc Med [Internet]. 2004 Sept [cited 2011 Oct 20];158(9):884-90. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/15351754>
- Indicadores de Mortalidade. Taxa de Mortalidade Perinatal [Internet]. 2012. [cited 2012 Jan 29]. Available from: <http://tabnet.datasus.gov.br/cgi/ibd2010/c15b.htm>
- Oliveira BRG, Viera CS, Collet N, Lima RAG. Causas de hospitalização no SUS de crianças de zero a quatro anos no Brasil. Rev bras epidemiol [Internet]. 2010 Jun [cited

2012 Jan 12];13(2):268-77. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1415-790X2010000200009

13. Leite NSL, Cunha SR, Tavares MFL. Empowerment das famílias de crianças dependentes de tecnologia: desafios conceituais e a educação crítico reflexiva Freireana. Rev enferm UERJ [Internet]. 2011 Jan-Mar [cited 2012 Jan 11];19(1):152-6. Available from: <http://www.facenf.uerj.br/v19n1/v19n1a25.pdf>

14. Neves ET, Cabral IE. Empoderamento da mulher cuidadora de crianças com necessidades especiais de saúde. Texto contexto enferm [Internet]. 2008 July-Sept [cited 2012 Jan 13];17(3):552-60. Available from: <http://www.scielo.br/pdf/tce/v17n3/a17v17n3.pdf>

15. Cabral IE. Desafios e perspectivas do cuidar de enfermagem na saúde da criança. Esc Anna Nery Rev Enferm [Internet]. 2009 Oct-Dec [cited 2013 Jan 17];13(4):691-3. Available from: <http://www.scielo.br/pdf/ean/v13n4/v13n4a01.pdf>

16. Porterfield SL, McBride TD. The effect of poverty and caregiver education on perceived need and access to health services among children with special health care needs. Am J Public Health [Internet]. 2007 Feb [cited 2010 July 21];97(2):323-9. Available from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1781389/>

17. Miller AR, Condin CJ, McKellin WH, Shaw N, Klassen AF, Sheps S. Continuity of care for children with complex chronic health conditions: parents' perspectives. BMC Health Serv Res [Internet]. 2009 Dec [cited 2010 Oct 18];9:242. Available from: <http://www.biomedcentral.com/1472-6963/9/242/about>

18. Brasil. Lei nº 8.080, de 19 de setembro de 1990. Dispõe sobre as condições para a promoção, proteção e recuperação da saúde, a organização e o funcionamento dos serviços correspondentes e dá outras providências. Brasília: DF; 1990.

19. Cabral IE, Perreault M, Leal RJ. Experiência Brasil-Canadá no cuidado social e na saúde da criança com necessidades especiais: aproximações e distanciamentos. Interfaces Brasil/Canadá [Internet]. 2010 [cited 2012 Jan 11];11:95-119. Available from: <http://www.revistabecan.com.br/arquivos/1277641441.pdf>

Submission: 2012/07/06

Accepted: 2013/03/08

Publishing: 2013/05/01

Corresponding Address

Eliane Tatsch Neves
Departamento de Enfermagem
Cidade Universitária/Camobi
Av. Roraima, 1000 / Prédio 26 / Sala 1336
CEP: 97105-900 – Santa Maria (RS), Brazil